

## **S. 1053 – Genetic Information Nondiscrimination Act of 2003**

Calendar No. 247

*Favorably reported by the Health, Education, Labor and Pensions (HELP) Committee without objection on July 31, 2003 with an amendment in the nature of a substitute. S. Rept. 108-122.*

### **NOTEWORTHY**

- A unanimous consent request was made to begin consideration of S. 1053, the Genetic Information Nondiscrimination Act of 2003, on October 2, 2003. Under the requested unanimous consent agreement, the Snowe amendment will be made in order. This incorporates the committee substitute amendment with additional findings.
- The measure, sponsored by Senator Snowe, prohibits discrimination on the basis of genetic information with respect to health insurance and employment. Both the original underlying bill and the manager's amendment have bipartisan support.
- In a June 19 report to the HELP Committee, the Congressional Budget Office estimated that the budgetary impact of this legislation would be minimal. CBO reported that the number of individuals obtaining insurance due to passage of the bill would increase by less than 500 people per year. As a result, federal revenues would decrease by less than \$500,000 in each year from 2004 and 2013 due to the tax deductibility of premiums paid by those newly insured individuals.

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## Highlights

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### **Framework**

The legislation recognizes that all individuals, whether they are healthy or sick, and all medical information, genetic or otherwise, should be afforded the same protections under the law.

### **Restrictions**

The bill prohibits insurance companies that offer coverage in the group or individual market from discriminating on the basis of genetic information or services. It also prohibits an issuer of a Medicare supplemental policy from denying or conditioning the issuance or effectiveness of a policy based on genetic information or services. It makes it an unlawful employment practice for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive such individual of employment opportunities because of genetic information.

### **Definitions**

The bill defines genetic information as genetic tests of an individual or family member or occurrence of a disease or disorder in family members. Genetic services are defined as tests, counseling, or education.

### **Privacy**

The bill protects the privacy of genetic information. The bill applies current Health and Human Services medical privacy rules to the use and disclosure of genetic information, but ensures that genetic information cannot be used for purposes of underwriting.

### **Enforcement**

Employment discrimination based on genetic information will be enforced under Title VII of the Civil Rights Act. Genetic health disclosure violations are enforced under Title I of the Health Insurance Portability and Affordability Act of 1996 (P.L. 104-191). In addition, health insurance discrimination violations generally will be enforced under the Employee Retirement and Income Security Act (ERISA) or state law.

### **Effective Date**

The law would go into effect 18 months after enactment. The bill directs the Department of Labor to issue regulations enforcing the law one year after enactment.

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## Background

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Recent scientific breakthroughs have opened new doors for medical researchers in analyzing DNA, RNA, and chromosomal changes. While the advancements yield promising hope for individuals diagnosed with rare genetic diseases, they also can lead to discriminatory practices in the health insurance market and in the workplace.

The Health, Education, Labor and Pension Committee has held five hearings on issues related to genetic discrimination in health insurance and employment since 1996. Although genetic nondiscrimination amendments have been adopted by the Senate, the measures were not enacted.

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## Bill Provisions

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### **Title I – Health Insurance**

The legislation applies to all health insurance markets, including employer-sponsored group health plans, group and individual health insurance issuers, Medigap policies, and state and local non-federal governmental plans, as well as federal plans. While the Employee Retirement and Income Security Act (ERISA) currently prohibits a group health plan or group health insurance issuer from discriminating against an individual by setting eligibility, premium, or contribution amounts based on the individual's genetic information, this legislation clarifies that genetic information includes "information about a request for or a receipt of genetic services by an individual or family member of such individual." S. 1053 extends such restrictions to insurance issuers in the individual and Medicare supplemental markets.

While group, individual, and Medicare supplemental insurance issuers are prohibited from requesting or requiring an individual to take a genetic test, the legislation specifies such prohibitions shall not interfere with the delivery of health care services. For instance, the measure does not limit the authority of the treating health care professional to request that an individual or family member undergo a genetic test. Nor does it limit the authority of a health care professional who is employed by or affiliated with a health plan or issuer from *notifying* an individual about genetic tests or *providing* information about a genetic test if such actions are carried out as part of a bona fide wellness program. However, the legislation does prohibit a health care professional from *requiring* that an individual undergo a genetic test.

Current law already protects the use and disclosure of all individually-identifiable health information, including genetic information. These protections are included under the Department of Health and Human Services (HHS) Standards for Privacy of Individually

Identifiable Health Information (medical privacy regulations; 45 CFR Parts 160 and 164; final rule). However, a permitted “use” of health information under the privacy rules (i.e., a specific item under ‘health care operations’) is underwriting – a practice that is inherently discriminatory. Therefore, the legislation expressly bans the use, disclosure, or collecting of genetic information for purposes of underwriting. The requesting, requiring, or purchasing of genetic information prior to enrollment also is prohibited.

S. 1053 uses enforcement provisions applied in current law. For instance, ERISA allows group health plan participants or the Department of Labor to sue for equitable relief. The bill further clarifies that with respect to a group health plan, a participant or beneficiary has the right to seek injunctive relief before exhausting administrative remedies if taking the time to pursue administrative remedies would cause irreparable harm to the participant’s health. Where a participant or beneficiary obtains equitable relief under ERISA for a genetic discrimination violation, the court has the discretion to reinstate coverage, retroactive to the date of violation and can award a penalty to the participant. The penalty amount payable to the individual is the same as the primary penalty that may be assessed by the Secretary under current law enforcement. For group health plans and health insurance issuers in the individual and group markets, the appropriate Secretary may impose penalties of \$100 per day/per person, with a minimum penalty of \$2,500 – up to \$15,000 for multiple violations that are more than *de minimis* with an outside cap of up to \$500,000 for a violation of the protections against genetic discrimination.

With regard to the privacy provisions, the same enforcement structure and penalties apply as created by the Social Security Act for the HHS privacy standards. The Secretary of HHS may impose civil monetary penalties of \$100 per violation – up to \$250,000 and 10 years in prison for violations committed for commercial advantage, personal gain, or malicious harm. Moreover, the bill incorporates the same penalty and enforcement structures granted under Title I of the Health Insurance Portability and Affordability Act of 1996 (P.L. 104-191) for nondiscrimination measures.

## **Title II - Employment**

The bill would prohibit employers, labor organizations, employment agencies and joint labor-management committees from using genetic information to discriminate against an individual through hiring, firing, or other employment decisions. Employers are also prohibited from requesting, requiring, or purchasing genetic information of employees. The genetic information protected extends to the employee, his or her spouse and all of their blood relatives, as well as adopted children. Employers who obtain genetic information about their employees inadvertently, through compliance with other laws (such as the Family and Medical Leave Act) or through certain efforts to preserve employee health (such as employee wellness programs or monitoring of biological effects of toxic substances in the workplace) would not be penalized unless they used such information to discriminate against the employee. The bill prohibits

disclosure of genetic information except to the employee, health researchers, or in compliance with federal and state law.

Penalties for violation of the law are those available under Title VII of the Civil Rights Act which prohibits employment discrimination based on race, color, religion, sex, or national origin. The procedures and remedies under the bill are the same as under current law. Employees who believe they have a claim must make a complaint to the Equal Employment Opportunity Commission (EEOC) or the appropriate state agency. The EEOC will investigate the claim and bring suit on behalf of the employee if evidence of a violation is found. The EEOC also may pursue mediation if the employer and employee agree to that option. In cases in which the EEOC chooses not to bring suit, the employee may bring suit independently. Penalties for Title VII violations include reinstatement, backpay, injunctive relief, equitable relief and attorney's and expert witness fees.

No charges may be filed for "disparate impact" discrimination, which is not an intentional adverse employment action but a discriminatory effect on a protected class caused by an employment practice or policy that appears to be nondiscriminatory. The bill would direct a commission to be formed six years after the bill's enactment to report on the possibility of allowing disparate impact claims.

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### Cost

The Congressional Budget Office (CBO) estimates that this bill would have a minimal budgetary impact. Specifically, CBO estimates that the number of individuals obtaining insurance due to passage of the bill would increase by less than 500 people per year. As a result, the measure would decrease federal revenues by less than \$500,000 in each year from 2004 and 2013 due to the tax deductibility of premiums paid by those newly insured individuals. For additional information, please refer to the CBO cost estimate of S. 1053 issued June 19, 2003.

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### Administration Position

Although a Statement of Administration Policy had not been issued at the time of this publication, the White House Office of Legislative Affairs says the Administrative is supportive of S. 1053 as reported.

## Possible Amendments

Except for the substitute offered by Senator Snowe, no other amendments are expected.

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